Updating the website launched in March 2000

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Elizabeth Bloomfield for OAARSN and GSA, 2009

Ontario Adult Autism Research and Support Network

OAARSN offers information and communication tools to connect adults with Autism, family members, caregivers, friends, support workers, teachers, administrators and policymakers. We can all benefit from the opportunities for mutual support and encouragement and the sharing of knowledge and experience. Our efforts to promote positive approaches and best practices in supporting adults with Autism can help all who live and work on the front lines.

OAARSN's focus on adult issues balances the emphasis on children in most other Internet resources about Autism Spectrum Disorders. OAARSN provides resources and links to share information about ASD, its various symptoms and types, current research, and helpful treatments and therapies—as these may be relevant to adults.

OAARSN was first launched in February-March 2000. Awareness of Autism has increased since then, with the huge growth of Internet information resources. There is still a role for OAARSN as an independent website representing all kinds of people concerned with adult Autism issues. The website has a simple and logical structure, with all features accessible from this homepage.

Autism Information addresses questions such as "What is Autism?", "How many people have Autism?", "What causes Autism?", "How is Autism diagnosed?", "Types of Autism" and "Autism in adulthood" and presents a summary of treatments and therapies for adults.

Autism Resources outlines the values and approaches that can support each individual with the complex needs to have the greatest quality of life. It also provides some guidance in searching for further Internet resources as well as to organizations that we have found helpful.

Creative Supports for Vulnerable Citizens outlines the larger context and values in creating a good life for all people with a disability—including supported decision-making, independent planning and facilitation (aka brokerage of personal supports), direct and individualized funding, building community capacity, and inclusion.

Document Centre presents links to PDF documents on the OAARSN site that may have lasting value—including perspectives on individual and family experiences,

statements of helpful approaches and methods, and accounts of special meetings and project plans.

Communications Centre has six sections, to which new materials are continuously added and announced in our OAARSN and Creative Supports news bulletins.
--Books on the Autism Spectrum
--OAARSN's Adult Autism News Bulletins
--Creative Supports Bulletins
--AROHA-Entities for Personal Empowerment and Support
--Bridges-Over-Barriers Communication Support Initiative
--Guelph Services for Adults with Autism

OAARSN was developed by Elizabeth and Gerald Bloomfield, based on a lifetime of support and advocacy with our son Andrew (born 1968). Our experiences convinced us that "there must be a better way!" We have realized the importance of sharing information and strategies that may help others.

This site is dedicated to the idea that adults with autism can continue to develop and learn. They and their primary caregivers deserve all the support, faith, imagination and patience we can give them. We who are directly involved believe in this idea because we know and love our particular adults and respond to their humanity. But even sceptics should ponder the social and economic benefits of encouraging continued development and increased quality of life.

We honour Andrew for being a brave pioneer, and his friends for their loyalty. We appreciate the dedication and ingenuity of Peter McCaskell in designing the first website in early 2000, and the support of the University of Guelph in hosting OAARSN on its web server. We thank Liana Rowlands of Guelph for working on this revised website. We value the connections made with members of the OAARSN, in Ontario, Canada and all over the world.

You may use this Search button to look up topics you are interested in--either on the OAARSN website or the whole World Wide Web.

DISCLAIMER

Please note that OAARSN provides resources for information purposes only. We do not endorse any treatment, program, product or service. The contents of this website are not medical, legal, technical or therapeutic advice. Information should be reviewed with qualified professionals. We will not be held responsible for misuse of information or for any adverse effects of recommendations mentioned on this website or on any other websites linked to it. Views, opinions or announcements posted by subscribers to any area of this site do not necessarily reflect those of OAARSN and we do not assume responsibility for any discrepancies or errors.

Ontario Adult Autism
Research and Support Network

What is Autism?

Since we first launched OAARSN in early 2000, this question is asked much more frequently, as popular interest and research have increased. But it is no easier to answer in 2009 than it was then.

Autism is a very confusing diagnostic label. The term is used both for a more specific syndrome of abnormal development and also for a much broader range of related disorders. As their causes are not yet known, these disorders are defined in terms of sets of behavioural symptoms which are not the same in every affected person. If we were to enter a room full of persons who had been diagnosed with Autism, we would be struck far more by the differences than by the similarities among them. Websites concerned with Autism usually present some information about the disorders, though some do not make clear the distinction between the more specific Autistic Disorder and the whole spectrum of autism disorders.

A great deal of research into Autism that has been reported since the early 1990s helps us to understand several features more clearly. There is general agreement that, in its full-blown form, Autism involves a **triad of impairments**—in social interaction, in communication and the use of language, and in limited imagination as reflected in restricted, repetitive and stereotyped patterns of behaviour and activities. People who combine all three impairments to a marked degree have the classic form of Autism, so named by Leo Kanner, a psychiatrist at Johns Hopkins University, in 1943, and termed Autistic Disorder in the *Diagnostic and Statistical Manual of Mental Disorders IV* (1994). But much larger numbers of people may have some of the traits of Autism.

The idea of a **spectrum or continuum of autistic disorders** is helpful to include persons who have some if not all the symptoms of Autism, sometimes in combination with other disabilities. Asperger's Syndrome, defined in 1944 but not widely used as a diagnostic label until the mid-1990s, may affect seven times as many people as Autistic Disorder (classic Autism).

We now know that Autism involves **disorders of development of brain functions**. It is not a mental illness. Nor is it psychogenic, caused by anything in a child's psychological environment. Earlier notions, that Autism was caused by emotional deprivation or emotional stress, have long been discredited. Autism affects families in all races, cultures and socioeconomic groups and is found everywhere in the world. More males than females are affected, the ratio being 4:1 with Autistic Disorder (classic autism), 9:1 with Asperger's Syndrome.

For a diagnosis of Autism, the main symptoms must be clear before the age of 3 years. The **disabilities are lifelong and there is no known cure**, though careful training and sensitive support can bring improvements. The autistic impairments may be associated with cognitive disabilities. Two-thirds of those with Autistic Disorder (classic Autism or Kanner syndrome) have been assumed to be mildly handicapped in cognition and intellect. Most people with Asperger's have average to higher IQ. Across the autistic spectrum, perhaps 10 per cent have distinctive abilities—in such fields as art, music, mathematics or memory—and may be called autistic savants. (The proportion of people with such special abilities in the whole population is only one per cent).

How many people have Autism?

Key studies in the 1960s, in sample regions in different parts of the world, found a ratio of 4.5 per 10,000 of the child population to have Autistic Disorder (classic Autism or Kanner's syndrome). By around 1990, a further 15 in every 10,000 were estimated to have what are sometimes called, in North America, other pervasive developmental disorders.

Research in the 1990s developed the concept of Autism Spectrum Disorders (ASD), with the aim of including people who might have some but not all of the key diagnostic features. British studies of sample regions estimated that 71 in every 10,000 have a milder form of ASD, mainly affecting social relationships rather than communication and language. About half of this larger number (36 in every 10,000 of the population) is estimated to have Asperger's Syndrome. These figures add up to 91 persons in every 10,000, nearly one per cent of the total population, which is the prevalence usually cited for the United Kingdom. At this rate, more than 60 million people around the world have some form of Autism.

In whole countries, such data are estimates rather than actual counts of people diagnosed. It is likely that many on the Autism spectrum have not been formally

identified, especially adults. Prevalence figures of one person in 150 or one in 166 are quoted in North America. Applying the rate of one in 150 to age-groups of Ontario's population at the 2001 census, we find the numbers in the following table, which may be compared with numbers for the narrower definition of Autistic Disorder.

Ontario: Estimates of Autism Numbers
(2001 Census)

Age group	Autistic Disorder ("Classic) 1 in 2,222	Autism Spectrum Disorder 1 in 150
0 – 4 years	302	4,473
5 –14 years	702	10,407
15-19 years	346	5,127
20-24 years	323	4,787
25-44 years	1,583	23,453
45-54 years	736	10,900
55-64 years	479	7,093
65 + years	662	9,813
Children (0-19)	1,351	20,007
Adults (20+)	3,784	56,060

An interesting and important question is: "Is the prevalence of Autism increasing?" Some people, notably advocates for services to young children, describe the increased diagnoses of some form of Autism during the past 15 years as an explosion, even a pandemic. In part, this probably reflects an enormous increase in awareness of Autism, so that professionals and parents recognize the symptoms of ASD much more readily than they did a generation ago. Another factor is the widening of criteria from Autistic DIsorder or classic Autism, to include the much broader concept of an Autism spectrum including Asperger's Syndrome as well as people who combine Autism with some other disability. Perhaps there has also been a real increase in the numbers and proportions of affected people—related to a wide range of environmental toxins and viral infections.

Another question is: "Does the prevalence of autism vary from place to place?" Autism has been found all over the world, in all societies and cultures, and in people of all ethnic and socio-economic groups. Some localities have been found to have very high concentrations of ASD diagnoses.

Since 2000, the volume of funded research into genetic, environmental and biomedical factors in Autism has increased enormously, but we are not yet able to answer these questions with any certainty.

What causes Autism?

Although they are not yet known, there are strong indications that the **causes of Autism Spectrum Disorders are biological.** The evidence includes the following observations.

- Autism is often accompanied by other neurological symptoms and associated with other learning difficulties.
- By adulthood, about one in three persons with Autism will have had at least two epileptic seizures.
- Most autistic children show unusual responses to sensory stimuli of any kind and have what have been called movement differences.
- Brain autopsies have shown abnormalities in the frontal lobes, limbic system, brain stem and cerebellum.
- Some 30 to 50 per cent of autistic children have abnormally high levels of serotonin, the chemical that transmits signals in nerve cells.
- The higher incidence of Autism in families points to a genetic aspect.
- There is evidence that at least one type of Autism is an immune-system dysfunction, its onset triggered by viral infections, or by antibiotics and vaccines.
- Some autistic children and adults are unable properly to digest certain foods or may have paradoxical reactions to medications.

It is extremely unlikely that Autism is caused by a single factor. It is most likely that certain people are genetically predisposed to be sensitive to any of various environmental insults that actually trigger the symptoms that we call Autism. Genetic research has identified several genes that may be mutated or damaged. And all kinds of environmental insults may be involved—from the myriad chemicals used in agriculture, forestry, industry and our homes to substances taken into our bodies as medicines or food. It is likely that Autism may be triggered in different people by varying combinations of genetic and environmental factors. This variability is reflected in the huge variety of particular symptoms and the differences that are so evident among people diagnosed with Autism Spectrum Disorder.

Since the late 1990s, there has been a major push to promote research into

the causes of Autism, with commitments by governments and charitable foundations to fund research. Various research centres have been set up, often as consortia of teams at several universities. Research findings are published at a quickening pace, in popular media as well as scientific journals.

Research on autism is welcomed as one sign of increased awareness of very challenging disabilities, after decades of neglect. However, we may be concerned if specialized genetic research may not take enough account of various causes that are needed to explain the distinct types of autism. Or if it is at the expense of study of approaches to treatments, interventions or services that could make help people already living with Autism.

How is Autism diagnosed?

Autism cannot be diagnosed by a simple blood test or brain scan, as some disorders may be. Diagnosis depends on a professional assessment of specific behaviours, usually in the first three years of life. When children are not identified till they are older, diagnosis may rely on parents' memories, records and videotapes. Adults, not identified when they were children for various reasons, may find that some degree of Autism Spectrum Disorder explains their lifelong sense of being different and perhaps some learning and social diffierences.

Autistic Disorder, as defined by the World Health Organization's *ICD-10 Classification of Mental and Behavioural Disorders* (1992), is distinguished into:

a) Childhood Autism, a pervasive developmental disorder defined by the presence of impaired development before the age of 3 years, with abnormal functioning in all three areas of social interaction, communication, and restricted, repetitive behaviour.

b) Atypical Autism, which differs from Childhood Autism in later age of onset or in insufficient clear evidence of abnormalities in one or two of the areas of impaired development.

North American professionals follow the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders,* the 4th edition (DSM IV, 1994) still being the current authority. DSM IV distinguishes five subtypes within the broader category it calls Pervasive Developmental Disorders, and prescribes the diagnostic criteria and associated features for each type:

a) Autistic Disorder or classic Autism, for children with severe qualitative deficits in all three areas.
b) Rett's Syndrome (see section on Types of Autism below).
c) Childhood Disintegrative Disorder (or Heller's Syndrome) which affects previously normal children who undergo massive regression between 2 and 10 years, resulting in severe acquired Autism, usually with loss of cognitive skills—but not because of schizophrenia or degenerative disease of the brain.
d) Asperger's Syndrome (see section on Types of Autism below).
e) PDDNOS (Pervasive Developmental Disorders Not Otherwise Specified) including Atypical Autism—the label for children with autistic behaviour who do not fit any of the other specific types in the spectrum.

To be diagnosed with Autistic Disorder, a child should show the following behaviours:
I: A total of six (or more) items from (A), (B), and (C), with at least two from (A), and one each from (B) and (C)

(A) Qualitative impairment in social interaction, as manifested by at least two of the following:
1. Marked impairments in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction.
2. Failure to develop peer relationships appropriate to developmental level.
3. Lack of spontaneous seeking to share enjoyment, interests, or achievements with other people, (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people).
4. Lack of social or emotional reciprocity (note: in the description, it gives the following as examples: not actively participating in simple social play or games, preferring solitary activities, or involving others in activities only as tools or "mechanical" aids).

(B) Qualitative impairments in communication as manifested by at least one of the following:
1. Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime).
2. In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others.

3. Stereotyped and repetitive use of language or idiosyncratic language.
4. Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level.

(C) Restricted repetitive and stereotyped patterns of behavior, interests and activities, as manifested by at least two of the following:
1. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus.
2. Apparently inflexible adherence to specific, nonfunctional routines or rituals.
3. Stereotyped and repetitive motor mannerisms (e.g. hand or finger flapping or twisting, or complex whole-body movements).
4. Persistent preoccupation with parts of objects.

(II) Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years:
(A) Social interaction.
(B) Language as used in social communication.
(C) Symbolic or imaginative play.
(III) The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

The term Pervasive Developmental Disorders was adopted by some Canadian professionals in the 1990s to include all variants and degrees of Autism recognized then. But other professionals as well as parents and caregivers are not satisfied with some of the labels and language of DSM IV, preferring the term Autism Spectrum Disorder (first used in Britain) which is now more commonly used.

Types of Autism

Several types have been defined along the Autism spectrum, differing in the severity of the symptoms and in the combinations of autistic impairments with other disabilities. We present brief accounts of some of these.

Classic Autism, Autistic Disorder or Kanner's Syndrome

The psychiatrist Leo Kanner of John Hopkins University first described and named this syndrome based on 11 of his child patients between 1932 and 1943. He noted the following common features:

- a profound lack of affect or emotional contact with others.
- an intense wish for sameness in routines.
- muteness or abnormality of speech.
- fascination with manipulating objects.
- high levels of visuo-spatial skills, but major learning difficulties in other areas.
- attractive, alert and intelligent appearance.

Kanner's observations became the criteria for early studies of the prevalence of Autism. Children (and adults) with these features have the full triad of impairments and represent the most severely disabled end of the autism spectrum of disorders.

Autism organizations were first formed in the 1960s and 1970s by the parents of children with classic Autism. More recently these organizations have been enlarged in scope and functions to serve all those with a wider range of symptoms on the Autism Spectrum.

Asperger's Disorder

First described by Hans Asperger of Vienna in 1944, whose work was not generally known in English translation until 1981, the disorder was not listed in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) until 1994.

Asperger's Disorder shares with Autistic Disorder a severe and sustained impairment in social interaction, and restricted and repetitive patterns of behaviour and interests. But people with Asperger's do not have the significant delays in language, cognition, self-help skills or adaptive behaviour that are typical in Autistic Disorder. They may be physically clumsy and awkward, more obviously than children with classic Autism. Asperger's is often not recognized easily or early, and may be misdiagnosed as Tourette's Syndrome, Attention Deficit Disorder, Attention Deficit Hyperactivity Disorder, Oppositional Defiance Disorder, or Obsessive-Compulsive Disorder. As with Autism, the disorder is lifelong and no complete cure is known. Asperger's Disorder may be the largest type on the autism spectrum, affecting 35 in every 10,000 people.

Some people with Asperger's may have an exceptional talent or skill with

which they are preoccupied. It is conjectured that several people of remarkable genius may have had Asperger's--including Albert Einstein, Vladimir Nabokov, Ludwig Wittgenstein, Bela Bartok and Andy Warhol. Of Canadian interest is the possibility that Asperger's Syndrome could explain Glenn Gould's social deficiencies, obsessive perfectionism and intolerance of change. This idea was raised in the 1996 biography by psychiatrist Peter Oswald, *Glenn Gould: The Ecstasy and Tragedy of Genius* and later elaborated by the musicologist Timothy Maloney. Gould was acutely sensitive to light, sound and temperature, and had a phobia about shaking hands as well as a limited range of preferred foods. His bizarre mannerisms as a concert performer could be understood as uncontrollable expressions of Asperger's.

Rett's Syndrome

First identified by the Australian Dr Andreas Rett in 1965, Rett's is a complex neurological degenerative disorder that affects only girls. It is rarer than some of the types on the Autism spectrum, affecting one in every 10,000 girls. From onset at about 18 months of age, its victims become profoundly and multiply disabled, and dependent on others for all their needs. Key symptoms include hypotonia (reduced muscle tone) and such autistic-like behaviours as wringing and waving hands. The discovery of the gene for Rett's syndrome was reported in October 1999.

Autism in adulthood

How relevant is diagnosis to our focus on adult Autism? For a diagnosis of Autistic Disorder (classic Autism) at least, the behavioral symptoms must be present before age three. Age of onset may be later for some of the rarer forms of Autism. And critical symptoms of some higher functioning forms of Autism, notably Asperger's, may not become clear until adolescence or adulthood.

Pediatricians and psychiatrists, in the past and perhaps sometimes today, may have been reluctant to pronounce a diagnosis of Autism out of consideration for the parents' feelings or because such a label was thought to close doors to service rather than open them. So many of today's adults who probably had key symptoms of Autism in early childhood were given other labels or described as having "autistic tendencies."

Autistic traits usually persist into adulthood, but with a wide range of

outcomes. Some adults with ASD achieve college degrees and function independently. Most diagnosed with classic Autism may not develop functional language and communication and may have poor daily living skills throughout their lives. Some adults with Autism who live without support may be reclusive or eccentric. Some may be labeled with obsessive-compulsive disorder, schizoid personality, simple schizophrenia, affective disorder, mental retardation or brain damage.

Those who probably had classic Autism as children may suffer from general assumptions that they have a poor prognosis as adults. It may not seem to professionals and policy-makers that they are worth much in resources. In recognizing other subtypes of Autism Spectrum Disorder, we may tend to overlook the needs of adults with the most distinctive and severe forms of the disorder.

By adulthood, in any case, the original symptoms of Autism may be masked by the person's life and treatment experiences, the effects of drugs, and her/his own efforts to cope with the disorder. Each person of whatever age should considered as a unique individual. This is especially true of adults who were diagnosed with Autism as children. Their challenges cannot be understood purely and simply in terms of Autism. On the other hand, knowledge of the Autism and past treatments may help in assessing their abilities and challenges as adults and in considering helpful approaches—including adult versions of therapies and strategies that may have been mainly designed for children, but too recently for today's adults.

In our view, far too little attention is paid to adult Autism as a general category of disability or to individual adults who have the symptoms of Autism. Yet adults with Autism are said to have normal life expectancy. It would be prudent as well as humane to assess each person's needs and abilities as part of individual plans for supports that will enable them to use their abilities, realize their dreams, and attain the best possible quality of life.

OAARSN's website is dedicated to the exchange of information about the needs and abilities of adults with Autism Spectrum Disorders, and about the most effective ways to support them to lead good whole lives.

Ontario Adult Autism
Research and Support Network

Treatments and Therapies

You, or your family member, have received a diagnosis on the Autism spectrum. What comes next? Can it be fixed? What can you do for yourself? Where can you get help?

Not only can it be a long and frustrating process to get a diagnosis. Families for decades have found it even harder to get a clear sense of what to do next. This was especially true in the past when there was less awareness of Autism. A few specialized services helped a few children, sometimes as an adjunct to research and training. Then as now, when a new treatment or therapy appeared to hold promise, parents and concerned professionals would flock to it, often to have their hopes disappointed. Most families felt lucky if they could just survive. They resigned themselves to a lifetime of care for their disabled member. Some broke under impossible strains, and gave up their autistic child or adult to some form of custodial care.

From the 1990s, we have seen a strong reaction against stoic acceptance or desperation. Special education is now mandatory in all North American jurisdictions. In what might be called a revolution of rising expectations, sufficient numbers of parents of young children are refusing to accept a life sentence for their autistic children and themselves. Two current expressions of this revolution in North America have been efforts to promote and fund research, and the wave of support for early intervention programs, especially those using Applied Behavior Analysis (ABA) techniques. Internet access has been very significant in these movements.

Various treatments and therapies have helped to make lives of people with Autism more bearable and meaningful, if none may actually cure their Autism. We outline some of them, with these cautions.

1. No single or simple cause of Autism is known: there is no magic bullet, no elixir, no quick fix.
2. Treatments and therapies used by and with persons with Autism did not usually develop from theories into practices. More commonly, observations of good or bad reactions to certain substances or experiences prompted a

notion that a particular approach might help. A good many of these treatments and therapies may have been developed for people with other disabilities, and were applied more recently to people on the Autism spectrum.

3. Given the range of persons affected by Autism and related disorders, the pervasiveness of the impairments, and the likelihood that Autism has several causes, no one form of treatment alone is going to be enough for any individual person.
4. A broader approach, based on developmental processes and relationships, may work better in the long term than a focus on only one symptom or problem area.
5. Each individual can benefit from a holistic approach, uniquely designed for his or her abilities, and drawing upon various treatments and therapies.
6. While most treatments or therapies have been proposed for children with Autism, some approaches could help some adults as well and are worth considering. We note, however, that some articulate adults strongly resist the idea that they need any form of treatment or therapy, and want only their distinctive differences to be accepted and respected by society.
7. What is the difference between a treatment and a therapy in the Autism context? Both terms may be used interchangeably, but may differ in shades of meaning. A treatment implies that it can or might cure a disease or challenging condition; it is more intrusive, may have side effects, and is usually based on a medical model. A therapy is a way of easing the symptoms and helping a person to have some quality of life; it is less intrusive, does no harm if it is not fully successful, and is usually based on relationships.
8. Thousands of print publications and millions of Internet pages have some information about treatments and therapies that might help someone with Autism. We comment on those in which we have some experience and which can be relevant to adults. We hope that others will add to the collective wisdom that accumulates in this site. Keywords may be used to search the Internet for website resources. Our OAARSN bulletins note news and resources as they come to our attention.
9. Our purpose is to provide an information service and opportunities for discussion. Please note our disclaimer: "OAARSN provides resources for information purposes only. We do not endorse any treatment, program, product or services. The contents of this website are not medical, legal, technical or therapeutic advice. Information should be reviewed with qualified professionals. We will not be held responsible for misuse of information or for any adverse effects of recommendations mentioned on

this website or on any other websites linked to it. Views, opinions or announcements posted by subscribers to any area of this site do not necessarily reflect those of OAARSN, and we do not assume responsibility for any discrepancies or errors."

Communication Therapies

Impairment of speech and language is a defining factor in the diagnosis of Autism in young children. At least one in three adults with Autistic Disorder does not speak, and a significant number who can utter spoken words may not be able to use language as an effective means of communication. Many challenging behaviours of people with Autism, such as aggression, self-injury, anxiety and depression, may be expressions of frustration at their inability to communicate effectively with others.

Traditionally, someone who could not speak tended to be dismissed as nonverbal and incapable of understanding or rational thought. Advocates of disability rights have gained a hearing for arguments that:

- Communication is the means by which all other rights are realized and is, in itself, a basic human right.
- Where people lack an adequate communication system, they deserve to have others try with them to discover and secure an appropriate system.
- No person should have this right denied because he or she has been diagnosed as having a particular disability.
- Presumption of intelligence in a person who cannot speak is the least dangerous assumption.
- Access to an effective means of communication is a free speech issue.

How have professionals and caregivers tried to help overcome this profound disability? People with Autism form part of the client group for **Augmentative and Alternative Communication (AAC)** for which the international body is ISAAC: http://www.isaac-online.org In Ontario, we also have Augmentative Communication Community Partnerships Canada (ACCPC), with its website at: http://www.accpc.ca/

These are some of the communication systems that can help:

1. Sign Language was developed for hearing-impaired individuals, but was often taught to autistic children in the 1970s. Signs and gestures were seen as a basic form of human communication and well suited to the good fine motor skills of children with classic Autism. Simultaneous use of sign and spoken language was

usually taught. Signed English is the best system of sign language, if sign and speech are being learned together, as its syntax matches that of spoken language. Signed Speech, or using sign and speech together, stimulated some children, who had previously been non-verbal, to begin speaking as well. At the time, it was imagined that people with Autism might live in group homes or other congregate settings, in which sign language would be the lingua franca. However, the general inability of most ordinary people to use and understand sign language means that this medium has been less effective in community settings. Autistic adults who know sign language usually have to have other forms of communication as well.

2. Picture Communication Symbols have been used since the mid-1980s, supported by the insights that some people with Autism think in pictures rather than words and so might learn better with visual cues than with spoken language. The **Picture Exchange Communication System (PECS)** uses stylized drawings--of everyday objects, activities and even relationships and feelings--that may be used to prompt steps in a complex task or to offer options among which choices may be made. Computer software is now available to make sets of PECS symbols that are appropriate to each person, but the vocabulary is usually designed for young children rather than adults.

3. Facilitated Communicating (FC) is a method of Alternative and Augmentative Communication (AAC) that is also called Supported Typing (ST) in Ontario. Since its introduction in the early 1990s, FC techniques seemed to help particularly adults and children who had not been able to speak because of their Autism. Some have been able with FC to break out of their isolation and to show clearly that "though they cannot speak, they have things to say." Some adults who have received help with FC or ST have been able to progress to independent typing and even speech. Some have been able to continue in literacy and further education programs, and a few have graduated from college. Even when users do not achieve independent typing, FC or ST can be a strategy to improve motor skills so they can make choices by pointing to or touching objects, pictures, letters, words or phrases.

A facilitator or communication assistant provides varying degrees of physical support, as well as emotional support, to the user of a communication aid. Such aids range from simple boards with numbers and alphabet letters to computerized devices with voice, display and printed output and can include arrays of pictorial symbols or photographs. The most common method involves the facilitator or assistant providing physical support in the form of backward

pressure as the communicator focuses on reaching forward to touch or type on the device.

A survey of FC and validation tests is presented in D. Biklen and D.N. Cardinal, *Contested Words, Contested Science: Unraveling the Facilitated Communication Controversy* (New York: Teachers College Press, Columbia University, 1997). Seven impressive communicators express themselves in the book *Autism and the Myth of the Person Alone* (edited by D. Biklen, New York University Press, 2005). Click for more: http://www.ont-autism.uoguelph.ca/FC-ST-2009.pdf

Ontario has the Bridges-Over-Barriers support group started by and for adults with Autism who use Supported Typing to share their successes, struggles and strategies. See the Bridges webpage on the OAARSN site: http://www.ont-autism.uoguelph.ca/Bridges-2007.html

4. Social Stories are a communication-based technique developed by Carol Gray of Michigan to help autistic children to know how to interact appropriately with others in social situations. The technique allows adults with Autism as well, to read, rehearse, and write in advance what to expect in social situations. Four kinds of sentences are used in any story:

- descriptive, telling what people usually do in particular social situations;
- directive, giving positive guidance to the individual as to how to act in specific situations;
- perspective, presenting others' reactions to a situation (something a person with Autism may finds hard to imagine);
- control, with strategies the person can use to help remember and understand the whole social story.

Social stories can help persons with Autism to become more independent in routines, and to know how to do an activity, how to ask for help, and how to respond appropriately to feelings of anger and frustration.

5. Lifelong Learning

Adults with quite severe Autism have too often been presumed to be incapable of growing and learning. When those around them have given up hope, a person may well conform to their low or negative expectations. But we have found that expressing confidence and hope and providing opportunities and interests are very worthwhile.

Adults who have found they can express their thoughts with FC or ST have asked for learning material and experiences, and some have gone on to formal

postsecondary education. Those whose intelligence was not realized when they were children deserve every encouragement, and show that it is never too late to learn when one is supported positively.

One aid to learning has been text-to-speech software like WriteOutloud, in which the learner may take in meaning three ways—through the eyes reading text of a chosen topic of interest, through touch when typing from the text, and through the ears when hearing the voice output of what one has typed. One man we know, who has a good varied life, finds typing with WriteOutloud to be a favourite activity which he can continue for up to three hours by himself. Later, in conversations using ST, it is clear that he has taken in and thought about the subject matter and ideas. Another man was over 50 when he first used WriteOutloud: the experience has stimulated him to speak with his voice so others can understand him at last (WriteOutloud is a product of Don Johnston Incorporated).

Education and Management Programs
Most methods are designed entirely for young children, though some proponents claim they could work with adults too.

1: Applied Behavior Analysis (ABA), Behaviour Modification or Lovaas Method
These techniques, formalized as the Lovaas Method from the 1960s, assume that all behaviour is learned through the consequences that follow. If a child likes the consequence, the behaviour will be repeated; if a child does not like the consequence, the behaviour is less likely to be repeated. This approach is based on the premise that children with Autism do not learn from their environment as normal children do, and therefore need a very intensive and structured learning program. Autism is viewed as a combination of numerous behavioural deficits that have to be changed to bring the child into our world. Three common techniques of behavior management are a system of rewards for appropriate behaviours, extinction of undesirable behaviors, and "Time-Out" or removal of the child by an adult from a problem situation. The intervention is advocated by families of children with Autism since the late 1990s in many parts of the world, especially North America. In Ontario, where it is funded for eligible young children at a unit cost of up to $80,000 a year, the intervention is also known as Early Intensive Behavioural Intervention (EIBI).

2. TEACCH methods (Treatment & Education of Autistic & Related Communication Handicapped Children) were developed under the leadership of Dr Eric Schopler in North Carolina from the 1980s. They also use behaviour

modification but in a more cognitive way than ABA, emphasizing skills the children already possess and using visual cues and schedule boards. The long-term goals are both skill development and fulfillment of fundamental human needs such as dignity, engagement in productive and personally meaningful activities, and feelings of security, self-efficacy, and self-confidence. To accomplish these goals, TEACCH developed the intervention approach called "Structured Teaching."

3. The Son-Rise Program at the Autism Treatment Center of America™ teaches parents how to develop and implement child-centred programs in their own homes. Parents encourage and motivate the child in activities that they observe he or she enjoys. The child is the teacher, on the belief that going with rather than against the child makes the child more motivated to explore and develop.

4. The Daily Life Therapy approach, developed by Dr Kiyo Kitahara of Japan, and practised at the Boston Higashi School, is holistic, based on relationships, and effectively combines elements of various specific therapies. The approach has three principles which foster human dignity and self-esteem and allow the child (or adult) to contribute to and benefit from society.

- Stabilize the emotions by creating known and predictable environments in which the person can master skills for independent living and thus feel accomplishment and pride.
- Establish rhythms of life and physical health and well-being through vigorous exercise, which helps to inhibit anxiety and increase self-control while decreasing aggressive and other behaviors.
- Stimulate intellectual and cognitive growth through a broad and age-appropriate curriculum (including language arts, mathematics and social sciences and with special attention to art and music) that allows individual interests and talents to flourish.

5. Gentle Teaching (or Compassionate Practices)
The methods outlined above are used predominantly with children rather than adults. Forms of Behaviour Modification may be tried when an adult with Autism has "challenging behaviours." A non-violent, non-aversive alternative teaches people with special vulnerabilities to feel safe and loved. Caregivers work to create feelings of safety and love in the context of a community of true companionship and interdependence.

Medication and Dietary Intervention
1. Medication

Our culture is conditioned to expect a medical cure for any ill. When something goes wrong, we look to physicians to prescribe some drug that will make it better. Various kinds of psychotropic drugs are used to help with specific symptoms of people with autism—such as attention deficit and hyperactivity, aggressiveness and destructiveness, depression, obsessions and perseveration, anxiety, self-injury, and seizures.

However, no specific medication has been developed or is approved to address all the symptoms of Autism Spectrum Disorders, which are various and complex, and no medication helps all people with Autism. Many people with Autism do not need drugs. And some suffer paradoxical reaction or side-effects which, in some people may be worse than the symptoms for which medication was prescribed. The use of any form of medication for persons with autism is contentious. On the one hand, it may seem unethical to administer drugs to people who cannot give informed consent. On the other hand, it is argued that if the life of a person with autism might be more bearable with medication, this should not be denied because of dogmatic opposition to all medication.

2. Diet Theories Relating to Autism

Parents in the past, observing that their autistic children had more difficulties when they had eaten certain foods, may have informally modified their diets. Some claim that children whose diet is modified early enough may recover from the symptoms of Autism. The publication of this book impressed parents of both children and adults with the potential for a cure: *Unraveling the Mystery of Autism and Pervasive Developmental Disorders: A Mother's Story of Research and Recovery* (by Karyn Seroussi, Simon and Schuster, 2000). Seroussi claimed her family had cured her son's Autism with the success of a gluten-free, casein-free diet before the child was 3 years old. The diet was combined with early and intensive learning programs.

Could dietary intervention help adults with Autism, who may now be found to be intolerant of gluten and casein? Hopes of any dramatic recovery might be slight, given the earlier years of developmental delays. But at least current digestive problems can be alleviated by removing casein, gluten and possibly other foods, leading to improvements also in sleep patterns, general outlook and behaviour. Little research has been published on diet and Autism in adults. But, in *A Positive Approach to Autism* (2000), Stella Waterhouse recommends that every child and adult with Autism be assessed professionally so that digestive problems, intestinal/bowel disease and/or food intolerances can either be ruled out or the necessary treatment implemented. Several theories proposing a link between diet

and Autism are discussed at: http://www.ont-autism.uoguelph.ca/diet-theories-SB.pdf

A diet that excludes certain foods must be carefully managed to ensure that all essential nutrients and micronutrients are included from alternative safe foods. At least some people with Autism appear to lack certain micronutrients (vitamins and minerals) that are needed for digestion or the functioning of the brain and nervous system, or that their systems do not use these substances effectively .The value of various vitamins in treating Autism was advocated from the 1960s by Dr Bernard Rimland, sometimes in very large dosages. As with the challenges of determining appropriate medication dosages, vitamins and other supplements pose similar challenges since they may vary in bioavailability and also be metabolized at different rates.

The implementation of a diet or its supplementation with vitamins, minerals or other alternative products should be done with the support of a health professional such as a registered dietitian or a physician.

.Sensory, Mind and Body Therapies

1. Sensory Integration

Pioneering a special field of occupational therapy in the 1960s, Dr Jean Ayres defined sensory integration as the process by which our brains process information from all our senses and use it to regulate our motor activities. Her works include Ayres, A. Jean (1973)..From the 1990s, her theories of sensory integration dysfunction, presented in works such as *Sensory Integration and Learning Disorders* (1973) were found to be relevant to understanding Autism as a neurological disorder that includes problems of perceptual and sensory processing and impaired motor skills. Experiences reported by autistic savants like Temple Grandin and Donna Williams have also helped our understanding. While most sensory integration therapists work with very young children, their insights and techniques can also work with teenagers and adults.

Sensory integration theory helps to explain unusual behaviours observed to some degree in most people with Autism. These include their abnormal perceptions of any sensory stimuli, and their responses expressed in "sensory defensive behaviours" as well as in high levels of anxiety and difficulties in attending to tasks, controlling impulses, tolerating frustration and balancing emotional reactions. Such behaviours are not consistent all the time or in different environments, and each individual has a unique combination. People with Autism may actually seek some sensations to block out other sensations, or they may

seem unresponsive because their nervous systems "shut down" to protect them from sensory overload. People with Autism show abnormal reactions to the more commonly understood senses of sight, hearing, taste and smell, but the theory of sensory integration is explained with special reference to three systems--tactile (touch), vestibular (movement and gravity), and proprioceptive (awareness of body position).

These insights have been developed into an understanding of the movement disorders or differences of persons with Autism (and others) as a result of their unreliable sensory feedback. These may be latent at all times, but most difficult when starting, executing, continuing, stopping, combining and switching movements or actions. Problems with sensory integration help to explain the behaviors variously described as stereotypic, self-stimulatory, impulsive, perseverative and non-responsive, as well as what others see as profound difficulties with communication and relationships.

Occupational therapists who work in this field have developed detailed assessment tools to measure sensory integration dysfunction and consistent strategies to manage challenging behaviour. Successful sensory integration techniques include the Wilbarger Protocol for Sensory Defensiveness, the Sensory Diet, general calming and alerting strategies, and advice for a wide range of specific problems. In *Building Bridges through Sensory Integration* (1998), advice is offered on adapting home, school and childcare environments and routines to be more consistent and predictable, as well as creative suggestions for activities, equipment and resources.

Special forms of occupational therapy that have helped persons with Autism:

1. Art Therapy is defined as a form of psychotherapy that utilizes art materials and the processes involved in making art. Art therapists have been working with children and adults since Autism was first recognized—to help them overcome their isolation by progressing developmentally, finding ways of coping, and gaining a sense of self and relatedness to the world.

Art materials and mark making are explored for their tactile and sensory qualities. Communication is encouraged by using both the representational and the expressive potential of art materials. The person with Autism is helped by the therapist to make some sense of their experiences and to develop confidence and self-esteem. A relationship is encouraged by the framework of a safe place and a regular time, with clear and consistent boundaries.

2. Music Therapy can make a difference in the lives of people with health or learning difficulties including Autism, by enhancing the quality of life and the psychological, physical, cognitive and social functioning. Music is nonverbal, not threatening, immediate in time, and naturally motivating and reinforcing. Songs, with lyrics composed like social stories, can be used to learn and practice social skills.

According to the Joint Declaration of the 1982 International Symposium of Music Therapists:
"Music therapy facilitates the creative process of moving towards wholeness in the physical, emotional, mental and spiritual self in areas such as: independence, freedom to change, adaptability, balance and integration... As the musical elements of rhythm, melody and harmony are elaborated across time, the therapist and client can develop relationships which optimize the quality of life."

Music therapy can help persons with Autism to:

- Improve self-image and body awareness,
- Increase communication skills,
- Increase ability of use energy purposefully,
- Reduce maladaptive (stereotypic, compulsive, self-abusive, disruptive, perseverative, impulsive) behaviours,
- Increase interaction with peers and others,
- Increase independence and self-direction,
- Stimulate creativity and imagination,
- Enhance emotional expression and adjustment,
- Increase attending behaviour,
- Improve fine and gross motor skills,
- Improve auditory perception.

3. Animal-Facilitated Therapy may help people with Autism who may think in some of the same ways as animals do. Temple Grandin, the autistic savant who designs livestock-handling equipment on the basis of her unique insights into animal behaviour, says that persons with Autism share with animals their thinking in pictures and by associations. They are also alike in having fear as their main emotion, especially fear of novel or unusual situations. This approach includes also riding, caring for and relating to horses and other animals, but has been most highly developed with dogs trained to support people with Autism.

Service dogs can be trained to support persons with Autism to cope with their sensory and social differences. Jim Sinclair, who has trained a series of service dogs to help him with his own autistic sensory difficulties, explains on his website the ways that dogs can help children and adults with Autism.

- One is by assisting them to modulate their sensory and motor behaviour.
- Second, dogs can help orientate their owners to their environments and may alert caregivers to any problems.
- Third, the social isolation of a person with Autism can be overcome when a service dog attracts positive attention and thus facilitates social interaction with others.
- Fourth, a dog's natural ability to learn routines can help its owner to learn a sequence of steps in a routine activity, while its ability to recognize and accommodate changes can help a person to be more flexible with unforeseen changes.

4. Horticulture as Therapy

The American Horticultural Therapy Association defines its focus as a complementary therapy profession that uses gardening and horticultural activities to improve and maintain physical health, mental health and social adjustment, recreational and leisure options, educational and occupational status. Horticultural therapy can enhance self-esteem, alleviate depression, improve motor skills, provide opportunities in problem solving, encourage work adjustment and social interaction, and teach marketable gardening and business skills. Some or all of these together help individuals to be more included in the everyday community.

People with various ills and disabilities can benefit from horticulture as therapy. Persons with Autism who have movement and sensory differences can be helped by the restorative powers of landscapes and healing gardens--the calm and quiet spaces, the integrity of designs and structures, the soothing greens with touches of brighter colours, the fragrances and textures and the feeling of protection and safety. The physical labour of working in gardens provides great opportunities for sensory integration as well as regular exercise in the open air, the pace can be adjusted to each person's abilities, and satisfying relationships are possible with friends and other gardeners as well as therapists. Those who have usually been in dependent relationships, receiving services from caregivers all the time, can experience the responsibility and dignity of a vital role in nurturing the plants.

Ontario Adult Autism
Research and Support Network

Autism Resources

Why Don't We Hear About Adults?

A generation or two ago, almost nobody knew about Autism except the tiny proportion of families whose children were diagnosed. Now Autism is always in the news, especially the service needs of young children. Have adults outgrown their Autism or recovered? No...

Very few Ontario adults with ASD have appropriate supports to lead good and fulfilling lives in their communities. Some younger and middle-aged adults may have pretty good lives because of the dedication of their parents.

As elsewhere in the world, the timely attention to the needs of young children on the Autism spectrum has not yet been matched by concern for the needs of adults.

Almost all suffer from general assumptions that they have a poor prognosis as adults. Professionals and policy-makers may not think that they are worth much in resources.

Most adults diagnosed with classic Autism were not supported to develop communication and social skills and may have poor daily living skills. There are almost no resources to help them to continue learning.

Too many have restricted lives in custodial care with no support for their autistic disabilities. Some are incarcerated with no social contact and some die tragic deaths. Professionals, agencies and caregivers may see autistic adults as mainly challenging because of their severe behavioural problems.

Most adults who probably had the symptoms of ASD in early childhood were not detected, or were given other labels, perhaps with "autistic tendencies." Those who were not diagnosed at all may have had social and learning difficulties in the

school years and, as adults, discover or suspect they have Asperger's or high-functioning Autism (HFA). But they can seldom get help.

Autistic adults who live without support may be reclusive or eccentric; they may be labeled with various mental health disorders and at risk for severe depression and suicide.

What have we learned of the needs and abilities of adults with Autism?
Autism is highly complex and affects each person in a unique combination of ways. Its multiple causes are not yet well understood.

Autism involves disorders of the brain, neuroimmune and gastrointestinal systems. The central impairment shared by people with ASD is general difficulty with social communication and relationships. Other symptoms may include hypersensitivities and reactions to any or all sensory stimuli, inability to speak or other difficulties with language, intolerance of various foods and drugs, sleep disorders, seizures, low muscle tone, movement differences, unusual fears, and obsessions with routines and order. The presence and severity of these symptoms vary in individuals. Those most severely affected may express their pain and frustration in behaviours that can hurt themselves and others.

A distinctive feature of people with ASD is the unevenness of their abilities and disabilities. While their development is affected by their disorders, they are not necessarily intellectually handicapped. Some who cannot speak can express mature and insightful thoughts when given the chance to communicate in other ways. Some people with ASD are highly intelligent and some have remarkable abilities in special fields including music, art, numbers, computers, and spatial reasoning. But these special abilities are usually at odds with their practical and social disabilities.

Whatever their original symptoms, autistic adults may also bear the scars of faulty assessments, treatments and teaching in the childhood and early adult years.

Perhaps the greatest difficulties are the barriers raised by other people's critical perceptions, attitudes and expectations.

What factors and strategies, starting in the school years, lead to best outcomes for adults with ASD?

1. A focus on abilities more than on deficits, and strategies based on observations of "what helps?" to balance assessments of "what's wrong?'

2. Respect for loving families as the experts on their daughters and sons with ASD and for their uniquely valuable experience and sense of responsibility.

3. A personal support network of friends of all ages who care and share time and interests.

4. Plans and strategies that consider each person as an individual. The more complex the disorder, the more individualized the supports must be.

5. Constructive co-operation among all involved to support a good, whole life of each person with ASD, including, as needed:

- Support to communicate thoughts and choices and to interact with others, in ways that work for each person
- Structured, predictable and familiar environments and routines, adapted as needed to suit each person
- Recognition of and help to cope with sensory stresses and transitions
- Work and recreational-leisure activities that give a sense of accomplishment and being valued
- Opportunities to continue learning
- A safe and caring home supported by companions one chooses
- Adequate and sensitive healthcare services
- Access to all necessary resources and expertise
- Advocates to ensure that rights and needs are respected and not violated, and that existing services are appropriate and adequate

Towards Better Lives and More Secure Futures for Adults with ASD

Start early, even from childhood, and keep evolving these interrelated strategies. Find more information about these good ideas and practices through searches of this and other websites, our Books on the Autism Spectrum section, and the OAARSN bulletins.

1. **Encourage self-expression and choices by whatever means.**

See the humanity, abilities and potential in your son/daughter, however severely challenged. "Listen" to them (even when they do not speak) to understand their point of view and priorities. Observe and record what strategies work best. See our Bridges-Over-Barriers section in the OAARSN Communications Centre.

2. **Find and keep friends of various personalities, ages and abilities, who get to know the person very well and can support and continue the parents' roles.**
Friends can support one another as well as the person when organized as a Circle or Personal Support Network. Each adult with ASD needs friends and allies in addition to family and those who are paid to be in her/his life.

3. **Plan with the person**
Planning tools developed by Inclusion, such as PATH (Planning Alternative Tomorrows with Hope), MAPS and CIRCLES, are helpful in working through transitions, envisioning a good life and devising strategies to attain it.

4. **Be creative and flexible in setting up key parts of the person's plan for a good life**
Don't be limited by the traditional service system. Consider what's really needed and find ways to make it happen. Have a clear understanding of your general goals. But also be open to the opportunities, even serendipity, at some unexpected turns in the PATH.

5. **Consider the best kind of living situation for each person.**
Adults with ASD need choices. A person with hypersensitivities may need her own home, supported in the ways she needs and shared with companions she chooses. Guelph Services for the Autistic (GSA) is pioneering a model of home ownership that includes choice and self-direction by the person, longterm capital investment by the family, support circles and networks, and recruitment and matching of lifesharers and supportive companions. See the GSA section in the OAARSN Communications Centre.

6. **Daily activities should be real and fulfilling and include continued learning, healthful exercise, and contributions to the community**
Each person should have a way of life that is uniquely suited to his needs and interests. He should be able to comment and make requests and suggestions. Support workers should be chosen by the focus person and carry out their wishes.

7. **A good life must be sustained, beyond the lives of parents.**
A new mechanism is the Aroha, an incorporated entity of personal empowerment and support (like a microboard in British Columbia). An Aroha can give good friends of the person and parents the legal powers to strengthen and continue family efforts. An Aroha can own property, and receive and manage resources to

match needs and wishes. See the Aroha Entities section in the OAARSN Communications Centre.

Links to Other Resources for Persons, Families and Caregivers Living with Autism
Electronic information about Autism has increased vastly—to 19.1 million references on the World Wide Web in March 2009, more than 63 times the number in early 2000 when the OAARSN website was launched. Adult Autism resources were very scarce then, and Autism issues in Canada hardly registered. In March 2009, an Advanced Google search for "autism spectrum disorders" combined with the keywords “adults” and “Canada” and excluding “children” finds 1,400 hits, three times as many as three years ago.

Some professionals and commentators completely pan Internet resources. Certainly, as with any innovation that is freely accessible, there is scope for error and misrepresentation. But the potential value of being able to look up new terms and to connect with others far outweighs the risks. A wise Internet searcher will look at a fair number of sources, looking for confirmation of what seems a good explanation, strategy or resource. We know that access to the Internet has empowered many who live with Autism. Of course, before embarking on any course of treatment, we should seek professional advice.

In the first edition of this website, we provided large numbers of links to all kinds of potential resources, throughout the OAARSN site. This time we are more selective. People seeking information and help can now browse the Web more easily. We also want to avoid having to update URL links to other websites too frequently.

We suggest the following advice for search strategies to be used with the Search function for OAARSN, and for the entire World Wide Web.
1. Think of the keywords that best match your interest, to type in the Search window.
2. Be specific in your keywords: just “autism” is far too general.
3. Try Google Advanced Search or Google Scholar, especially if you are seeking research information. Using Advanced Search to look for information about biomedical issues for adults with autism, those keywords would all be entered and you may also specifically exclude “children” and “youth” to narrow your search.
4. You’ll probably want to avoid the sponsored links. Otherwise, the links are displayed more or less in order of likely relevance to your keywords.

5. A fair portion of the hits may be personal anecdotes or questions or advertising of products or services, rather than balanced expert advice.
6. Don't believe everything you find. Try to weigh up the evidence, look for confirmation in several sources, and consider the relevance to your situation and needs.
[Insert link here for Google Search function for OAARSN and whole WWW]

We recommend this **tutorial guide to further searching on the Internet** http://www.lib.berkeley.edu/TeachingLib/Guides/Internet/FindInfo.html#New. Also **Autism Data**: a brief guide to searching (National Autistic Society UK) http://www.autism.org.uk/nas/jsp/polopoly.jsp?d=1534&a=8438, as well as **Research Autism** of NAS:
http://www.autism.org.uk/nas/jsp/polopoly.jsp?d=1466&a=15092

More specialized resources may be used in specific fields of concern: **PubMed** http://www.ncbi.nlm.nih.gov/sites/entrez, for example, is a service of the US National Library of Medicine that includes over 18 million citations from MEDLINE and other life science journals.

Autism Ontario http://www.autismontario.com, incorporated in 1973, now has more than 30 regional and local chapters throughout the province. Find links to all these chapters in window at top right of the home page. Since 2004, Autism Ontario has led a partnership group of Ontario organizations and groups in advocating with the Ontario Government for the well-being of adults and youth with ASD. See more about these efforts http://www.autismontario.com/adults including details of the manual: *Living with ASD: Adolescence and Beyond* (2006). *Forgotten* (2008)
http://www.autismontario.com/Client/ASO/AO.nsf/object/Forgotten+Report+Autism+Ontario/$file/Forgotten+Report+Autism+Ontario.pdf
is a public policy paper addressed to the Government of Ontario, with recommendations for supports and services for Ontario adults with Autism & adults with Aspergers.

The Geneva Centre for Autism in Toronto http://www.autism.net offers resources, training and conferences for professionals, parents and other caregivers. Its services are mainly focused on children and youth with Autism, but some approaches are also useful for adults.

Kerry's Place Autism Services, http://www.kerrysplace.com, incorporated in 1974, pioneered specialized services for adults with Autism in Ontario. It now offers a comprehensive range of supports, including residential and other living supports for adults, as well as programs of community outreach, clinical services, supported independent living programs, respite care and crisis support for adults, youth and children with Autism Spectrum Disorders in several Ontario regions.

AutismConnects http://www.autismconnects.com/ is a "Virtual Community of Autism Spectrum Stakeholders." People with ASDs, their families and friends, educators, therapists, service providers, organizations, researchers, legislators and volunteers – anyone with an interest in Autism and a desire to improve the health and quality of life of people with ASDs – are invited to become members.

Aspergers Society of Ontario http://www.aspergers.ca/ was founded in 2000 to provide education, resources and support to individuals diagnosed with or considering a diagnosis of Asperger Syndrome.

Autism Society Canada http://www.autismsocietycanada.ca/index_e.html is a federation founded in 1976 of Canada-wide provincial and territorial Autism societies, that is committed to advocacy, public education, information and referral, and support for its regional societies. Look for links to *Report of the Advisory Committee of Adults with Autism Spectrum* (2007) and *Life with ASD: Resources for* Adults *and Youth.*

The National Autistic Society (UK) http://www.autism.org.uk/, founded in 1962 and thus the world's oldest autism society, offers a rich variety of resources on its website and is a model for other national and regional organizations. To mark its 40th anniversary, the NAS has focused sharply on adult issues, with its influential *Ignored or Ineligible?: The Reality for Adults with Autistic Spectrum Disorders* http://www.autism.org.uk/content/1/c4/28/61/ignored.pdf. The **I Exist** campaign http://www.autism.org.uk/nas/jsp/polopoly.jsp?d=1558&a=15394, launched in 2008, highlights the impact of the lack of support on adults with autism and the action that is needed to bring real improvements to people's lives.

Creative Supports for Vulnerable Citizens

For the past ten years or so, Ontario has seen a movement towards more individualized supports and services for adults who live with a disability. Values and principles include planning with the person, a central role for families and friends, and designing supports that match what the person really wants and needs to enjoy a good whole life in the community. Key phrases that have become current include "self-directed planning with choice and control", "supported decision-making", "individualized funding," "independent facilitation (or brokerage) of personal supports" that is responsible to the person with a disability, "self-advocacy—nothing about me without me!," "community inclusion and participation," and "circles of friendship" or "networks of personal relationships."

Some of these concepts and ideals go back two or three decades among forward-thinking people. Only rarely were they put into practice in Ontario. Families who tried to do so usually met resistance from Government policy-makers and funders and the traditional service agencies. As elsewhere, people with developmental disabilities still bore the stigma of dependency-- charity cases qualifying for support from public funds at the lowest possible level and as a last resort. People who did qualify for funded services had to fit into narrowly prescribed categories, rather than having supports shaped to their real needs and abilities.

There are now hopeful signs that people with disabilities in Ontario may have more choice and control over their lives. In 2004, the Ministry of Community and Social Services began a process of consultation with representatives of many of the stakeholders. An official report on this process was published as *Opportunities and Action – Transforming Supports In Ontario for People who have a Developmental Disability* (May 2006). New legislation, *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008*, is replacing the earlier 1974 act governing Ontario's services for people with developmental disabilities.

Since 2006, some initiatives have been funded that embody some of the new principles. For example, Passport provided funding for activities in the community for people with a developmental disability who have left school. People with developmental disabilities, their families and community agencies were also encouraged to develop new and innovative residential models to help them live in the community. Pilot projects of independent planning and facilitation have been supported in a few places.

Pathways to Inclusion: Building a New Story with People and Communities (2007), by Drs John Lord and Peggy Hutchison, describes the process of transforming services and supports for persons with a developmental disability. They contrast the way people experienced the traditional service model with the values and principles of the "new story" that is exemplified in various projects in Ontario and across Canada. See **OAARSN's review with more publication details.** http://www.ont-autism.uoguelph.ca/Pathways-review.html

Since the mid-1990s, the Individualized Funding Coalition for Ontario has been active as a loose coalition of groups, family members and individuals who are concerned with supporting people with a developmental disability. IFCO has fostered understanding of the values and principles, advocated more creative supports to allow for choice and control by the people being supported, and monitored current realities. IFCO in partnership with other organizations that provide creative supports launched a Trillium-funded project in 2007. **Modeling Community Change and Innovation (MCCI)** http://www.modelingcommunitychange.com/backgrounder.html involves "the collaboration of three communities in Ontario that are building support for individualized approaches for citizens with a developmental disability. A Trillium grant is being used to develop community readiness, strengthen autonomous groups, resource materials, and sustainable community plans. This project will assist people with disabilities, and their families/networks to direct their own lives and live as healthy, participating, contributing citizens as they build a good life for themselves in community." The MCCI initiative includes a website and the production of print and electronic materials to encourage other communities and autonomous groups as well.

We find that creative supports and the values and principles they embody are highly relevant to the very individual and complex needs of adults with Autism. So OAARSN has been an active supporter of such ideas and practices.

Look up **OAARSN's graphic ten-step process** for realizing an independent personalized plan. http://www.ont-autism.uoguelph.ca/STRATEGIES8.shtml#TOP

Links to Other Resources about Creative Supports

1. OAARSN maintains a Listserv for a network of people interested in Creative Supports, and issues regular Creative Support bulletins with notes of current news and issues and announcements of events and publications. Link for current page about the **Creative Supports bulletins and Listserv.** http://www.ont-autism.uoguelph.ca/CS-Bulletins-html

Link for archives of past **Creative Support bulletins from 2003 to 2008.**
http://www.ont-autism.uoguelph.ca/CS-archive-20032008.html
In case any of the many URL links may be no longer active on other websites, as can happen, you might try to cut and paste the text title into your browser, in order to find a current link or similar materials.

The OAARSN website includes a browser for the Google Search function to reach resources on the OAARSN website and the whole World Wide Web.

2. Modeling Community Change and Innovation
Browse the **Resources page of the MCCI website**
http://www.modelingcommunitychange.com/resources.html
Note these titles:
Resource papers written in partnership with the Individualized Funding Coalition for Ontario
What is Person-directed Planning
What is Independent Planning and Facilitation
Elements of a Good Person-directed Plan
A Good Planning Process

A resource written by David DeVidi
The I in Independent Planning and Facilitation: Why should Facilitation be Independent?

A resource from the Individualized Funding Coalition for Ontario
Our Vision

3. **The Individualized Funding Coalition for Ontario**
http://www.individualizedfunding.ca/resources.html
You may download the following publications by IFCO or its partners:

Independent Planning and Facilitation
"The Signature Paper" Transformation of Developmental Services: Expanding the Possibilities for Citizenship (January 2007).

Rationale for Independent Planning and Facilitation in Ontario: Why MCSS Should Move Quickly to Implementation (November 2006)

Creating a Good Life in Community: A Guide on Person-Directed Planning (2006).

Citizenship, Participation and Transformation

Common Vision Newsletters, Part One and Part Two (2005)

Statement of Principles: What a direct individualized funding support system would look like for a person when these four dynamic principles are at work (November 2006)

Building a New Story: Transforming Disability Supports and Policy. Revisiting In Unison: Reflecting on the In Unison document and where things are at now in relation to Transformation (September 2005)

The Need for Change (November 2003)

Individualized Funding: Research and Reports in Ontario
Moving Toward Citizenship: A Study of Individualized Funding in Ontario (2006).

More Choice and Control for People with Disabilities: Review of Individualized Funding (July 2000)

"The Round Table Report" Linking Individualized Supports and Direct Funding. Making Money Work for People - A Pathway to Self-Determination and Community Involvement for People with Disabilities (May 2000).

4. **Inclusion.com** http://www.inclusion.com/
Inclusion Press of Toronto offers books, videos and other materials for learning and training about Circles of Friends, MAPS Making Action Plans), PATH (Planning Alternative Tomorrows with Hope), Creative Problem Solving, and Tools for Teams.

5. **PLAN** (Planned Lifetime Advocacy Network) http://www.plan.ca/ is a non-profit organization, established in 1989 by and for families committed to future planning and securing a good life for their relative with a disability. Founded in British Columbia, PLAN now has affiliates in most Canadian provinces. PLAN has been chiefly responsible for the acceptance of the Registered Disability Savings Plan. PLAN's proven model is explained in a book by Al Etmanski, *A Good Life—for you and your relative with a disability* (2000). Families are guided to set up personal networks and plan the future security of their relatives with disabilities through seven steps and 15 family worksheets.

Ontario Adult Autism
Research and Support Network

Books on the Autism Spectrum

OAARSN first launched this important feature in July 2000. This first edition, including reviews and lists of books and other media, is still useful and may be reached at: http://www.ont-autism.uoguelph.ca/books.shtml

We now start a new series of notes and reviews of various resources. These will be highlighted in the OAARSN news bulletins, and links to reviews etc are listed below in reverse date order.

Our region has a remarkable resource of books and other information materials about Autism Spectrum Disorders. The Kitchener Public Library, with funds given by Waterloo-Wellington Autism Services, established a special Autism Collection of books and other media in 2004. In early 2009, there are now more than 800 titles. Click for more about how to use this resource, within the region and by inter-library loan: http://www.ont-autism.uoguelph.ca/kpl-autcoll.html

Please click on this hot key for a live list of the titles of all the books, videos etc, in alphabetical order: Search KPL Autism Collection You can then use the *Sort/Limit* button at the top of the screen to narrow down to what you are really looking for – such as the author's name. Or you can request the date order, so all the new items come to the top. Or you may limit by type of medium to find videos or DVDs.

Jessica Kingsley Publishers, independent publishers of accessible professional and academic books in the social and behavioural sciences, have a major subject category on Autism Spectrum Disorders and related topics. Visit http://www.jkp.com/

Parentbooks of Toronto has been serving families and professionals in Canada and around the world since 1986. Visit http://www.parentbookstore.com/ All prices are in Canadian dollars and are subject to change without notice.

201 Harbord Street, Toronto, Ontario M5S 1H6
Open Monday through Thursday 10:30 am to 6 pm.
(416) 537-8334 or 1(800) 209-9182 or Fax (416) 537-9499 or
email parentbk@netcom.ca

BOOKS NOTED OR REVIEWED FOR OAARSN
Many other book notes and reviews may be mentioned in the OAARSN News Bulletins. Those in our first edition, focusing on the period to 2004, may be reached at: http://www.ont-autism.uoguelph.ca/books.shtml
Please send messages about Books on the Autism Spectrum to OAARSN at oaarsn@gmail.com , including "Books" on the subject line.

2008
Pathways to Inclusion: Building a New Story with People and Communities by John Lord and Peggy Hutchison. Captus Press, ISBN 978-1-55322-165-4 (2007). Approx. 270 pages, 500 g, 6 X 9, $29.50 (US$26.75). *Reviewed by J. Edward McCartney*
http://www.ont-autism.uoguelph.ca/Pathways-review.html

Ontario Adult Autism
Research and Support Network

OAARSN's Adult Autism News Bulletins

Shortly after launching the original OAARSN website in March 2000, we began a Listserv network which has grown to include contacts all over the world.

Bulletins of news and announcements are compiled and posted on the OAARSN website every 2-3 weeks. A bulletin may include:

- Autism news
- Research reports
- Announcements of forthcoming events
- Invitations to take part in research projects
- Reviews of new books and other resources
- Writings about life on the autism spectrum

People on the OAARSN Listserv are sent an email note of the URL link to reach the latest bulletin.

OAARSN welcomes discussion of ideas and topics related to Autism as it is experienced by adults and their families and companions. We support freedom of information and expression, and encourage everyone to try to see all sides of issues and to understand the viewpoints of others.

Please note that this service is for information and awareness. OAARSN and the University of Guelph cannot endorse or be held responsible for the validity of any information or the value of any service or resource that may be announced or mentioned in these bulletins. Nor do we necessarily agree with opinions that may be expressed.

We are willing to post announcements, but ask that you provide the details as follows:
Please send submissions in plain text format by email to oaarsn@gmail.com

with "announcement" at the beginning of the subject line.
Please provide details of the following as BRIEFLY as possible:
..Name of Event
..Sponsor of Event
..Main Speakers and Topics of Event
..Date of Event
..City and Location of Event
..Contact information for more information/registration
..URL Link to learn more about event
Please Do Not Attach Files, Flyers or Brochures as we do not attach these to our email bulletins.

Link for archive of past OAARSN bulletins, 2002-2008:
http://www.ont-autism.uoguelph.ca/OAARSN-bulletin-archive-20022008.html
In case any of the many URL links may be no longer active on other websites, as can happen, you might try to cut and paste the text title into your browser, in order to find a current link or similar materials.

The OAARSN website includes a browser for the Google Search function to reach resources on the OAARSN website and the whole World Wide Web.

Links to OAARSN bulletins from January 2009

- February 12, 2009
- January 29, 2009
- January 8, 2009

Creative Supports Bulletins

While organizing the Focus on Microboards events in Guelph in November 2001, we came to realize that people and families living with other handicapping conditions besides Autism were interested in the information functions of OAARSN. So we created a new Listserv for everyone who is vulnerable because of any kind of disability, and for their families, friends and supporters. Numbers of interested people have grown through our hosting the conference about Creative Supports for Vulnerable Citizens in April 2005.

This is an electronic bulletin for adults who are vulnerable because of disability and for their families, friends and supporters who care about them. Through the bulletins, we can share dilemmas and difficulties, bright ideas and successes. There are announcements of events and special projects, discussions of issues, concerns about public policies, and links to useful books, websites and other resources. Our focus is mainly on Ontario, but we have wider contacts as well. People on the Listserv are sent an email note of the URL link to reach the latest bulletin.

The Creative Supports Bulletin and Listserv are linked to the OAARSN website (Ontario Adult Autism Research & Support Network) which is hosted at the University of Guelph. We welcome discussion of ideas and topics related to Creative Supports for vulnerable citizens. We support freedom of information and expression, and encourage everyone to try to see all sides of issues and to understand the viewpoints of others.

Please note that this service is for information and awareness. OAARSN and the University of Guelph cannot endorse or be held responsible for the validity of any information or the value of any service or resource that may be announced or mentioned in these bulletins. Nor do we necessarily agree with opinions that may be expressed.

We are willing to post announcements, but ask that you provide the details as follows:
Please send submissions in plain text format by email to oaarsn@gmail.com *with "announcement" at the beginning of the subject line.*
Please provide details of the following as BRIEFLY as possible:
--Name of Event

--Main Speakers and Topics of Event
--Date of Event
--City and Location of Event
--Contact informationor URL Link to learn more about event
--URL Link or other for more information/registration
Please Do Not Attach Files, Flyers or Brochures, as we cannot include attachments with our bulletins.

Link for archive of past Creative Supports bulletins, 2003-2008:
http://www.ont-autism.uoguelph.ca/CS-archive-20032008.html

Links to Creative Supports bulletins from January 2009
February 11, 2009

Person-Centred Homes and Support Networks

AROHA-Entities for Personal Empowerment and Support

The most valuable resource for a person with a disability, as for anyone, is a circle of friends or personal support network. For someone who is vulnerable, it may be good to consider incorporating an entity to supplement or succeed the role of parents in ensuring the person has a good life.

The first Aroha in Ontario was incorporated as a legal entity in 2002, with and around a man in Guelph who is also a founding member of OAARSN. This Aroha has shared its experience with other circles of families and friends who want to incorporate.

An Aroha entity can be helpful in many circumstances, whether or not it is a person wants to live in a home of his own. Each vulnerable person and situation is different and unique.

An Aroha ensures that the focus person's voice is heard and that available resources and supports are used for the individual, in keeping with her or his wishes and needs—now, and into the future, after parents are no longer available to take care of the many details that add up to quality of life.

An Aroha can have legal powers to:
a) receive and administer individualized funding directly from Government
b) administer trust funds set up by families
c) be the employer of record for support workers
d) own and maintain property such as the home of the person with a disability
e) make contracts and agreements with independent service providers and consultants
f) make contracts with facilitators and agencies that may provide direct and infrastructure supports
g) carry liability insurance.

Link to OAARSN webpage about Aroha-Entities, including the following sections:

http://www.ont-autism.uoguelph.ca/entities.shtml
-Questions and Answers
-Guelph Focus on Microboards (report of a workshop in 2001)
-Guide to Incorporating an Aroha: Models: Strategies, Objects and Bylaws
-Story of Ontario's First Aroha

To reach information about Aroha-Entities, please send a message first to OAARSN at oaarsn@gmail.com

Bridges-Over-Barriers

A creative communication group was started in 2004 by six Ontario men who live with quite severe challenges of Autism. As they do not speak with their voices, other people might assume that they have nothing to say—even that they do not think or feel. But they are very expressive, on many topics, supported by AAC technology (alternative and augmentative communication) and the presence of family and friends who believe in them. The idea of meeting regularly began with one of the men, who also proposes agenda topics and acts as host. Family members and friends just facilitate the dream in practical ways--and listen! The men gather in Guelph from all over southern Ontario, and there are corresponding members in faraway places too.

The pioneers have a dream of Bridges-Over-Barriers as *"a centre for friends and family who live with the challenges of autism to come together to share support, ideas and community. Bridges is the beginning of an idea for us to build on a small community of adults with autism who have been meeting a few times a year since January 2004. We have been developing our skills as communicators and sharing technology ideas and friendship.*
"We want to extend this community of pioneers to include more people. We would like there to be more opportunities for others to benefit from our experience, and to encourage and train more people to support those of us with communication and movement disorders."

Members of Bridges share the philosophy of "People First": "Nothing about me without me" and "Though I may not speak with my voice, I have plenty to say." Friends and families of the men like the potential of Bridges-Over-Barriers to help with supported decision-making, and are supporting them to start realizing the vision.

They share a vision of helping more adults who use supported typing and other forms of AAC to express their thoughts and dreams. The newsletter (see links below) contains more information on specific projects, such as a demonstration DVD, a resource manual, and an IT system designed to enhance communication among the group in both real and virtual gatherings.

Some of the men express themselves in poetry, some of which may be found in the Bridges-Over-Barriers newsletters. *In My Mind* is a published collection of

thoughts and words (often expressed as poetry) by one of the Bridges group. Click for more about In My Mind

Two Bridges newsletters were published in 2006, one in 2007, and the latest in November 2008:
Click for Newsletter 1, 2006
Click for Newsletter 2, 2006
Click for Newsletter 3, 2007
Click for Newsletter 4, 2008
Click for Newsletter 5, 2008
Click for Newsletter 6, 2008

To communicate with Bridges-Over-Barriers, please send a message first to OAARSN at oaarsn@gmail.com

Person-Centred Homes and Support Networks

Guelph Services for Adults with Autism

Families and friends in Guelph-Wellington have been concerned about adults with Autism since the 1970s. Founding members of the local chapter of what is now Autism Ontario hosted colloquia and designed service proposals for teens and adults. In 1980, they incorporated Guelph Services for the Autistic as a charitable, not-for-profit corporation in Ontario, and later also co-founded Waterloo-Wellington Autism Services in 1991 when the Ontario Ministry of Community and Social Services agreed to provide funding for pilot projects in the combined region.

See an account of these early efforts. http://www.ont-autism.uoguelph.ca/Aut-Well.html.
Records relating to Autism organizations and initiatives, in the region and Ontario generally, are held in a special **Autism Collection at the Wellington County Museum and Archives**. Search for Title=Autism at this link:
http://www.wcmaonline.on.ca/~collection/search/archives_web/srchitem.html

GSA reorganized in 1997 to be a housing trust for adults with Autism Spectrum Disorders. It is not an agency, receives no direct funds from the Ontario Government, has no paid staff, and depends on the efforts and gifts of volunteer members and directors. Support mechanisms being pioneered by GSA are attracting interest elsewhere and being followed as models. GSA published a guide in 2008 to describe its role as housing trust: ***Creating a Home and Good Life of My Own.*** See **an outline, links to excerpts and how to order.** http://www.ont-autism.uoguelph.ca/Creating-home-2008.html
GSA's support model is outlined in a presentation to the Minister of Community and Social Services in 2002, on **promising initiatives in the Guelph region**:
http://www.ont-autism.uoguelph.ca/Prom-Init-oct02.html

Important values and priorities of GSA:
1. Focusing on the individual person:
   - individualized funding supported by independent planning and facilitation

- self-directed life plans for good lives of dignity in home communities
- choices of how and with whom to live
- encouragement of self-expression and supported decision-making by whatever communication modes work most reliably
- friends and family "listening" to and empowering the person
- adults with whom GSA has housing agreements are its only "active members" (other supporting people are associate members)

2. Fostering natural social relationships with support from among family, friends, neighbours, community:

- circles of support/personal support networks
- friends and family providing natural social supports
- Aroha entities of personal empowerment and support
- community inclusion: contributing to and being present in the community

GSA's present roles:

- Trusteeship role in owning and maintaining a home with and for each active member, with various legal agreements to protect the person
- Developing more life/living supports, such as "anchor" and companion homesharers
- Attracting volunteer friends for adults and their families
- Outreach function, encouraging and empowering other families in Waterloo-Wellington-Dufferin region to learn from pioneer support models
- Sheltering the Aroha-entities and Bridges Over Barriers initiatives
- Information service through OAARSN (Ontario Adult Autism Research & Support Network) website and the OAARSN Adult Autism News and Creative Supports electronic newsletters
- Sending representatives to workshops and conferences on relevant issues
- Organizing colloquia and conferences in this region—such as Autism and Community in 2004; Creative Supports for Vulnerable Citizens in 2005; Brokerage for Personal Supports and Resources for Adults with Autism in 2006.
- Counseling and support networking among adults with Autism and their families and friends.

Link to GSA's Annual Report for 2005 http://www.ont-autism.uoguelph.ca/GSA-AR-2005.pdf, marking the 25th anniversary of its incorporation.
To communicate with GSA on its role as a housing trust, please send a message first to OAARSN at oaarsn@gmail.com, with GSA on the Subject line.

Ontario Adult Autism
Research and Support Network

Document Centre

Note: Most of these documents are in PDF format, and can be read with Adobe software.

Section 1: Organizations and Newsletters

Adult Autism Issues in Waterloo-Wellington (AAIWW) – Joint Newsletters of Guelph Services for the Autistic and Waterloo-Wellington Autism Services

- No. 33, August 2006
- No. 32, August 2005
- No. 31, June 2005
- No. 30, February 2005
- No. 29, January 2005
- No. 28, November 2004
- No. 27, October 2004
- No. 26, August 2004
- No. 25, May 2004
- No. 24, April 2004
- No. 23, February 2004
- No. 22, December 2003
- No. 21, October 2003
- No. 21, October 2003
- No. 20, Summer 2003
- No. 19, April 2003
- No. 18, January 2003
- No. 17, October 2002
- No. 16, August 2002
- No. 15, May 2002
- No. 14, February 2002
- No. 13, November 2001
- No. 12, September 2001
- No. 11, June 2001
- No. 10, March 2001

- No. 9, November 2000
- No. 8, August 2000
- No. 7, May 2000
- No. 6, February 2000
- No. 5, Winter 1999-2000
- No. 4, Autumn 1999
- No. 3, Spring 1999
- No. 2, Fall 1998
- No. 1, Summer 1998

Section 2: Needs Surveys and Reports and Service Plans and Proposals

- ASPIRE: Autism Support Project: Information, Resources, Empowerment 2002-2005
- Autism and Community: A Vision and Strategic Plan for a Farm Community and Regional Centre (2004)
- Summary of Proposed WWAS Service Model (1992)
- Our Most Vulnerable Citizens: A report of the Adult Task Force, Autism Society Ontario, 1991 (produced by GSA for Autism Society Ontario)

Section 3: Individual and Family Experiences

THE CHALLENGES OF AUTISM: a mother's perspective on 30 years' living with autism, published in *ANN: The Bulletin of A New Network Within The Presbyterian Church in Canada*, Vol. 3, No. 3, November 1999.

Tale of Three Dogs: how a man with autism values his companion dogs (1999).

Isaac's Story: Isaac is quite severely handicapped by the symptoms of Autism. He does not speak with his voice and finds it hard to express himself in ways that others can easily understand. He tries, but cannot always control his movement disorders and sensory integration dysfunction. His life has been hard for him in various ways. But insights into how Isaac experiences Autism and the efforts of his parents and friends to help him get his life together have been succeeding. Isaac allows his true story to be shared so it may inspire others. He hopes others will feel encouraged by knowing that he has taken several steps towards a better life. Isaac's story has messages for others who live with severe challenges--though the same combination of strategies that have worked for him would not work in exactly the same way for another person who

lives with the symptoms of autism or similar neurological or communication differences. Isaac's Story was first published on OAARSN in instalments in 2001. Click on the title to read the full story so far.
Kevin's Empowerment Group By Joan Gray

Section 4: Perspectives on Abilities and Inclusion

I am Disabled
Author Unknown, quoted in SJU Autism and Developmental Disabilities List
Beyond Programs--a parable
Michael McCarthy; reproduced from Contact, Sept/Oct 1991
What everyone yearns for--really good support to communicate
By Andrew Bloomfield
The Quiet Voice
By Judith Snow
LISTEN
By Tony Diamanti, tdiamonti@hotmail.com
My Personal Speech
By Tony Diamanti, tdiamonti@hotmail.com
PATH: Planning Alternative Tomorrows with Hope
As part of its ASPIRE project, GSA encouraged persons and families to use PATH as a creative planning tool for the future. Here are some ideas about PATH and CIRCLES to plan better lives and more secure futures, based on a PATH workshop and several PATH events for young adults with ASD.
Community is not a place but a way of life
From a speech by Herbert Lovett in Dallas, May 1996
Thoughts on Worship
by Beryl Forgay in Regina, Saskatchewan
Keeping the Balance
By David and Faye Wetherow.
Designing Accommodations - some things to consider.
Copyright A.M. Donnellan and M.R. Leary 1997, with contributions by Jayne D. Miller, Mary Lapos, Carole Doran, Judy Marquette and the writings of Donna Williams.
Sensory Integration: An Approach to Help with Self-Regulation and Skill Development.
Elizabeth J. Bell, BScOT, OT(c)